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AUTHOR Reever, Karen E.; And Others
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ABSTRACT

Frequently, the principle reason for institutionalizing cognitively impaired older persons is the caregivers' inability to continue providing help, and not the severity of deficits. Factors related to the caregivers' feelings of burden in a sample of 29 community-living older persons with senile dementia were investigated. Caregivers were spouses (N=18) and daughters (N=11). The extent of cognitive deficit of the impaired person, caregivers' reports of memory and behavior problems, the amount of social services received, frequency of visits from relatives and friends, and problems in activities of daily living, were examined by a structured interview. Feelings of burden were significantly correlated with the frequency of visits made by others, but not with other variables, including the severity of cognitive impairment and frequency of memory and behavior problems. (Author)

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RELATIVES OF THE IMPAIRED ELDERLY: CORRELATES OF FEELINGS OF BURDEN

Karen E. Reever, M.P.A./M.S.G., Julie Bach-Peterson, M.S.G. and

Steven H. Zarit, Ph.D.

Andrus Gerontology Center

University of Southern California

Los Angeles, CA. 90007

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The chronic diseases leading to senile dementia, which affect 5 to 10 percent of the older population, result in cognitive impairments and memory loss that generally leave the afflicted person in need of supportive care. While placement is often made into nursing homes or other protective settings, the majority of older people with senile dementia live in the community rather than an institution (Bergmann, 1975; Kay et al. 1964). Family members are the main caregivers providing most assistance or supervision that is needed (Bergmann et al. 1978). Community care of persons with senile dementia and other chronic illnesses has many advantages (see Kahn, 1975; Kahn and Zarit, 1974), but often places a major burden on family members or other caregivers. The present research investigates factors related to the amount of burden experienced by the principal caregivers of older persons with senile dementia. The purpose of this study is to identify sources of that burden, thereby facilitating the development of interventions to reduce caregiver's burden.

Senile Dementia in the Community

In recent years the gerontological literature has stressed the importance of finding alternatives to institutionalization because of its negative effects especially on the impaired elderly. Some studies have reported especially high rates of mortality among relocated dementia patients compared to those remaining in the community (Blenkner, 1967). Furthermore, because of their inability to retain new information, dementia patients may show greater impairment in unfamiliar settings, while in their own homes familiar cues can often trigger well established habits (Plutzky, 1974).

Epidemiological evidence indicates that most older persons with senile dementia can and do remain in the community. Bergmann (1975) has estimated that the average finding of community surveys is that 4.2% of the over-65 community population have senile dementia. Kay et al. (1964) found severe mental deterioration to be present in 4.9% of their older British community sample and mild mental deterioration to be present in 5.2% of those 65 and over. Approximately 90% of the organically impaired older people in that study lived in the community rather than institutions.

Factors that threaten the impaired person's ability to remain in the community have not been greatly researched. Bergmann et al. (1978) found family support to be the most important factor. He observed that older people with senile dementia in the community were most likely to stay there if they were living with relatives, particularly relatives other than a spouse.

Lowenthal (1964) discussed specific behaviors that increase the likelihood of institutionalization of older mentally impaired people. The most salient of these behaviors include disturbances in thinking and feeling and potentially harmful behavior. Such behaviors are common with the dementia client. Lowenthal also observed that when the burden and distress felt by caregivers exceeded their capacity to cope, the mentally ill older person is usually institutionalized. This raises the question as to whether or not the behaviors which appear to augment institutionalization also intensify caregivers' burden.

Sainsbury and Grad (1970) examined the impact of community versus hospital care on the burden of caregivers of dementia patients. Behaviors found to be particularly worrisome to caregivers included potentially harmful behavior to self or other, behaving oddly, restlessness, and being troublesome

at night. Several of these worrisome behaviors are the same as those found by Lowenthal to predict institutionalization. Again, the interrelationship among symptomatic behaviors, burden of caregivers, and institutionalization is suggested but not explicitly examined or discussed.

Sanford (1975) measured the tolerance of caregivers toward problems encountered in giving care to mentally impaired older people. Caregivers found the lack of time for themselves and sleep disturbances the most difficult circumstances to tolerate. Assuming that burden and tolerance are inversely related concepts, Sanford's study suggests the association between specific behaviors of older people with dementia and their caregiver's feelings of burden.

The Community Study of Caregivers

Because of the importance of family and other informal supports to maintain persons with senile dementia in the community, the present investigation examines how caregivers feelings of burden are affected by the impairments manifested by the dementia patient and by various aspects of the home care situation. An interview to assess the level of burden experienced by caregivers was developed and has been studied in relation to the behaviors affected by senile dementia, including the occurrence of behavior and memory problems and the degree of functional and cognitive impairment. The burden of caregiver's has also been examined in terms of social factors affecting care of the dementia patient, such as the amount of formal and informal support the caregiver receives and other situational characteristics.

Older people with senile dementia (N=29) and their primary caregivers (N=29) were interviewed. The mean age of the subjects with dementia was 76 years. This group consisted of 16 white males and 13 white females. All but four of the caregivers interviewed were female, 18 being spouses and 11 daughters. Someone was designated as the primary caregiver if they were principally responsible for providing or coordinating the resources required by the person with dementia, such as housekeeping, financial help and shopping. The age range of the caregivers was 42 to 82 years with a mean age of 65. Subjects were recruited from a research and training center offering counseling and memory training to older persons.

Interviews took place in the home of the dementia subject. The home setting was chosen because it was felt that familiar surroundings were less stressful and provided a more accurate picture of the older person's ability to function. Each interview took about 1 1/2 hours to administer.

The presence of senile dementia was determined by pre-screening subjects with the Kahn Mental Status Questionnaire (MSQ) and the Face-Hand Test (FHT). These tests, when administered together, have shown good validity with psychiatric diagnosis of senile dementia (Kahn et al. 1960). While sometimes criticized as insensitive to mild degrees of dementia, these tests have the advantage of yielding few false positive results, thus reducing the likelihood of including older people without senile dementia in the sample (Kahn and Miller, 1978). Two or more mistakes on the MSQ and any mistakes on the FHT after four learning trials were considered an indication of dementia.

The level of cognitive impairment of the dementia patient was indicated by scores on the two screening measures (MSQ and FHT) and by the 30-item mental status test developed by Jacobs et al. (1977). While containing items of orientation that are identical with the MSQ, this test also includes twenty

other questions that tap mental speed, reasoning, learning, calculations and the ability to maintain and shift sets. This test thereby samples more areas of cognitive functioning that can be impaired with dementia than the Kahn MSQ.

The Memory and Behavior Problems Checklist determined the types and frequency of memory and behavior problems exhibited by the impaired older person. Caregivers were asked to read through a list of 16 common memory and behavior problems, such as "wandering or getting lost" and "having embarrassing, rude or objectionable behavior", and then indicated how often this behavior occurred in the past month. Total memory and behavior problem scores were generated for the number of different problems occuring and their frequency.

It was expected that caregiver's burden would increase as functional abilities of the caregiver and older person with senile dementia decrease. To determine the level of functional ability of the subject with dementia, Lawton's (1971) Physical and Instrumental Activity of Daily Living scales (PADL and IADL) were used. These tools assess the levels of assistance required by the older person with senile dementia to do physical activities such as dressing and walking as well instrumental activities such as using the telephone. A short version of the IADL was used to determine the caregiver's difficulty in performing daily activities.

The measurement of the degree of burden was made with a 30-item self-report inventory, which was administered to the primary caregiver during the assessment interview. Statements that describe typical concerns of those caring for older people were presented. Examples of items used are "I feel my spouse tries to manipulate me" and "I feel that I am contributing to the well-being of my spouse." The caregiver indicated how much these statements described their feelings by choosing the most appropriate phrase from "not at all" to "extremely." A total burden score was calculated and used in the analysis. The complete interview appears in Table 1.

Demographic data, including age, sex, education, income and relationship of the caregiver to the subject with dementia, was gathered on all subjects. The duration of the illness was determined from a history obtained from the caregiver. In addition, caregivers were asked about the frequency of visits of other family members to the dementia patient, and if any formal social or health services were being provided.

Factors Associated with Feelings of Burden

An examination of the interview and test results indicated that the sample of 29 subjects with senile dementia had considerable cognitive and behavioral impairment (Table 2). Scores on mental status tests were generally low. There was a range of 0 to 9 on the Kahn MSQ, with a mean score of 3.6 out of 10 possible correct responses. Subjects made an average of 7.7 correct trials out of a possible 16 on the Face-Hand Test. The Jacob's MSQ scores were similar with a range of 0 to 22 and an average score of 11.4 out of a possible 30 correct. The average duration of dementia was reported to be 3.1 years, with a range from 6 months to 10 years.

Scores on measures of functional ability and frequency of memory and behavioral problems associated with senile dementia also indicate that this sample is substantially impaired in many areas. From a list of eight possible memory problems, 62% of the caregivers indicated 4 or 5 of these problems occured within the past month. The most frequent memory problems included asking repetitive questions, losing things and forgetting what day it is. Behavior problems occured less frequently, with only 18% of the sample reporting 3 or more problems in the past month from the checklist of 8 items. Neglecting self care and restlessness were the most frequent behavior problems, reported by 34% of the sample.

Of the measures of functional ability of the impaired subject, instrumental activities of daily living required the most attention from caregivers. Two-thirds of the impaired persons needed at least some help with most of these activities. Mean scores were 14.0 out of 24 on the IADL scale and 18.6 out of 21 on the PADL scale with higher scores indicating more independence. Physical activities, such as eating, walking and toileting, were less affected by dementia, with most subjects independent in these areas.

About 9 visits per month from family other than the primary caregiver to the older person with dementia were reported by our sample. Frequency of visits ranged from as few as no visits to as often as daily visits. For this study family includes children, grandchildren and siblings. Children were the most frequent visitors (5 visits per month) when compared to grandchildren (2.9 visits per month) and siblings (1.3 visits per month).

The level of burden measured was less than expected considering the complexity of many of the cases. The mean score was 31 (range 1-66; s.d.=13.8) out of a possible 100 on the burden interview. Items on which the most burden was reported involved the caregiver's lack of time for oneself, the excessive dependency of the patient on the caregiver, and caregiver's fears about further deterioration in the patient's behavior.

It was expected that feelings of burden would be related to the extent of behavior impairment manifested by the person with senile dementia. Contrary to expectations, none of the behavior variables, including the frequency of memory and behavior problems, the extent of cognitive impairment on the mental status tests, and the level of functional impairment on the IADL and PADL scales, were correlated with the level of burden (Table 3). Similarly, duration of the illness was not related to burden. Of the remaining measures, only the frequency of family visits was significantly related to level of

burden ($r = \underline{-0.48}$, $p < .01$). The negative correlation indicates that subjects receiving more visits from children (other than the primary caregiver), grandchildren and siblings had caregivers who reported less burden.

Since some caregivers were spouses and others were daughters of the impaired person, it was decided to test whether the relationship of the caregiver to the impaired person affected the findings. Separate analyses were carried out for subjects whose caregivers were spouses and for those whose daughters provided the assistance. As shown in Table 2, there was no difference in the feelings of burden reported by daughters compared to spouses, or in the level of impairment of persons with dementia in the two subgroups. Correlations were also made on the relation of burden to the other variables within each subsample. As with the whole sample, burden was inversely related to number of family visits to the impaired person's household for both daughters ($r=-0.66$) and spouses ($r=-0.47$). No other variable was significantly associated with feelings of burden.

Feelings of Burden and Community Care

The surprising aspect of this study is that feelings of burden reported by primary caregivers of persons with senile dementia were not related to the behavior problems caused by the illness, but were associated with the social supports available, specifically the number of visitors to the household. Previous research on the impaired elderly has stressed that specific behaviors are troublesome to family members, for example, wandering and insomnia, as well as the amount of time involved in providing assistance, but the frequency of these problems was not found to contribute to feelings of burden. Clearly, such things as severe memory loss and the problems associated with it are distressing to family members, but the ability of caregivers to

cope with that situation may depend on the other supports available to them. No information was elicited on what visitors were doing or the quality of the visits, which undoubtedly affect the degree of relief caregivers receive. Nonetheless, the sheer quantity of visits from other family members was important.

An important limitation of this study is that caregivers did not report what could be considered high levels of burden. All of the caregivers had decided, at least for the present, not to institutionalize the person with senile dementia. They may, therefore, not be representative of all families caring for individuals with this disorder. On the other hand, the extent of behavioral impairments found in the dementia patients indicates they had a fairly extensive degree of difficulty and were not mildly impaired or in the early stages of the illness. In a few cases the duration of the disorder was as long as 10 years. Hence, though the sample may not have been representative, problems resulting from dementia which were faced by these caregivers covered a wide range of severity and duration.

One implication of these findings is that an intervention program that increases informal social supports may be effective with a caregiver who reports excessive feelings of burden. Professionals can provide this service directly, by forming a supportive counseling relationship with involved family members. In an analogous situation Pasamanick and his associates (1967) reported that home visits made by public health nurses to families of schizophrenics had a beneficial effect on patient outcome. The supported home group of schizophrenics showed less hospitalization and a greater percentage of time at home than controls not receiving the visiting program. The main role of the public health nurse was to listen to clients and their families and to offer some counseling. This listening was felt to be the crucial element in the success of the home care group.

Another means of delivering support is through group meetings for the caregivers of older people with senile dementia. Hudis (1977) has found that such group meetings give members an opportunity to share concerns, clarify problems and roles, and develop skills for problem solving and coping. It is also an efficient means of educating caregivers about senile dementia and community resources that may be useful. The mutual support among group members may generate self-help groups run by members themselves.

It is also possible to work with the entire natural support network of the person with dementia to provide assistance to the primary caregiver. Garrison and Howe (1976) describe how network therapy can be used with those with senile dementia. The goal of network therapy is to use affective and instrumental resources present within the natural support network to promote coping with problem behaviors. By helping the entire natural support network to share in the supportive care of the older person, the responsibilities on the primary caregiver are reduced and, hence, burden may be lessened. The results of family meetings held by the authors have been encouraging, increasing the amount of help given to the primary caregiver and increasing the understanding of the situation by everyone involved.

For those older people who have no natural support network or need additional network members, the use of a natural neighbor has been demonstrated in the literature. A natural neighbor has been defined as someone to whom people turn to for assistance on an informal basis (Patterson, 1977). Collins and Pancoast (1976) describe how to find, build and maintain a consulting relationship with a natural neighbor. Community volunteers can also be used to fortify the natural support network of the impaired older person. With one or a combination of these interventions one can attempt to enhance the supportive function of a natural support system and relieve excessive burden on the primary caregiver.

Summary and Conclusion

In summary, this research looks at the possible factors contributing to feelings of burden on those caring for older people with senile dementia. Caregivers and older persons with senile dementia living in the community were interviewed in their homes. Of the variables considered, including the extent of cognitive impairment, memory and behavior problems, functional abilities, and the duration of illness, only the frequency of family visits had a significant effect upon the caregiver's feelings of burden. In situations where more visits were paid to the impaired older person from family other than the primary caregiver, burden was less.

The strong relation between visits from family and caregiver's burden is important to service providers focusing on the needs of the older person with senile dementia. It suggests that primary caregivers would be best served by interventions that involve other members of the impaired older person's natural support system and make use of the resources within this network. Several methods of intervention with a natural support system have been described including network sessions, discussion groups, the use of home visitors and natural neighbors.

The decision to institutionalize an older person is often made to protect involved family members from excessive burden. The present study suggests that enhancing the informal support network of the older person with dementia may also prevent overwhelming burden on the primary caregiver and the breakdown of the family system, thereby reducing the rate of institutionalization.

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Table 1: The Burden Interview.

1. I feel resentful of other relatives who could but who do not do things for my spouse.
2. I feel that my spouse makes requests which I perceive to be over and above what s/he needs.
3. Because of my involvement with my spouse, I don't have enough time for myself.
4. I feel stressed between trying to give to my spouse as well as to other family responsibilities, job, etc.
5. I feel embarrassed over my spouse's behavior.
6. I feel guilty about my interactions with my spouse.
7. I feel that I don't do as much for my spouse as I could or should.
8. I feel angry about my interactions with my spouse.
9. I feel that in the past, I haven't done as much for my spouse as I could have or should have.
10. I feel nervous or depressed about my interactions with my spouse.
11. I feel that my spouse currently affects my relationships with other family members and friends in a negative way.
12. I feel resentful about my interactions with my spouse.
13. I am afraid of what the future holds for my spouse.
14. I feel pleased about my interactions with my spouse.
15. It's painful to watch my spouse age.
16. I feel useful in my interactions with my spouse.
17. I feel my spouse is dependent.
18. I feel strained in my interactions with my spouse.
19. I feel that my health has suffered because of my involvement with my spouse.
20. I feel that I am contributing to the well-being of my spouse.
21. I feel that the present situation with my spouse doesn't allow me as much privacy as I'd like.
22. I feel that my social life has suffered because of my involvement with my spouse.
23. I wish that my spouse and I had a better relationship.
24. I feel that my spouse doesn't appreciate what I do for him/her as much as I would like.
25. I feel uncomfortable when I have friends over.
26. I feel that my spouse tries to manipulate me.
27. I feel that my spouse seems to expect me to take care of him/her as if I were the only one s/he could depend on.
28. I feel that I don't have enough money to support my spouse in addition to the rest of our expenses.
29. I feel that I would like to be able to provide more money to support my spouse than I am able to now.

Table 2: Mean Scores and Standard Deviations of Characteristics of the Dementia Sample for All Subjects and Two Subsamples.

Variable	Mean Score (Standard Deviation) Total Sample (N=29)	Daughters as Caregivers (N=11)	Spouses as Caregivers (N=18)
Mental Status			
Kahn MSQ	3.6 (2.8)	3.4 (3.6)	3.7 (3.1)
Face Hand Test	7.7 (6.9)	7.2 (6.3)	8.0 (7.4)
Jacobs Questionnaire	11.4 (7.3)	11.3 (8.1)	11.4 (7.1)
Duration of Illness (yrs.)	3.1 (2.2)	3.8 (3.2)	2.7 (1.3)
Frequency of Memory Problems (per month)	96.1 (38.7)	118.5 (36.2)	82.4 (34.2)
Frequency of Behavior Problems (per month)	30.2 (39.9)	44.3 (39.0)	21.7 (39.0)
Physical ADL	18.6 (3.0)	18.5 (3.4)	18.7 (2.8)
Instrumental ADL	14.0 (4.7)	14.1 (3.4)	13.9 (5.4)
Frequency of Family Visits (per month)	9.3 (9.8)	14.4 (13.4)	6.1 (5.0)
Caregiver's Level of Burden	30.8 (13.8)	28.3 (14.6)	32.5 (13.4)

Table 3: Correlations between Characteristics of the Dementia Sample.

Variables	Mental Status	Duration of Illness	Memory Problems	Behavior Problems	Physical ADL	Instrumental ADL	Family Visits
Duration of Illness	-0.30						
Memory Problems	-0.17	0.40*					
Behavior Problems	-0.30	0.46*	0.45*				
Physical ADL	0.19	-0.51*	-0.46*	-0.76*			
Instrumental ADL	0.51*	-0.46*	-0.48*	-0.44*	0.59*		
Family Visits	0.05	-0.27	-0.20	0.00	0.22	0.27	
Caregiver's Burden	0.06	0.02	0.16	-0.07	-0.06	-0.20	-0.48*

* = $p < 0.05$; N=29.